



Multiple Sclerosis
Association of America **Webinar Transcript**

Program Title: “Losing Connection: Difficult Decisions in a Virtual World”
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MSAA Host: **Amanda Montague, Vice President of Education and Healthcare Relations**

Amanda Montague: Hello. And welcome to everyone joining us today. First of all I want to thank you very much for being here and for our webinar, Losing Connection: Difficult Discussions in a Virtual World.

This webinar has been sponsored by EMD Serono and we at MSAA are delighted to be joined by our colleagues from MS in the 21st Century for today's webinar. I'm Amanda Montague, the Vice President of Education and Healthcare Relations at MSAA.

And we're honored to have with us today Professor Giovannoni, Professor of Neurology at Barts and the London School of Medicine in the U.K.; Mitzi Williams, Neurologist, the Joi Life Wellness MS Center out in Atlanta, Georgia; and Stanca Porta, a patient expert from Romania.

Before we delve in, I'd like to provide a little bit of context about this collaboration. MSAA is a national non-profit organization founded over 50 years ago. MSAA is dedicated to improving lives today through ongoing support and direct services to individuals with MS, their families, and their care partners.

MSAA leads navigating MS, a global initiative designed to improve outcomes for people with MS to improving the way that healthcare professionals, patients and care partners communicate around benefit and risk in their MS management.

MS in the 21st Century is much aligned with the work that MSAA is doing in this area. MS in the 21st Century is an international steering group of healthcare professionals and people living with MS aimed at improving communication in MS care and developing resources based on real world needs.

We've got a lot to cover, so let's get started. And one brief note; if you do have a question, you'll see the box on the lower left. Please feel free to enter in your question and we will try to answer as many of those as we can at the end of the presentation.

So today we're going to be talking about an issue which has impacted all of us around the world during this COVID pandemic. How can we effectively communicate with our physicians in an online environment?

Telehealth is being practiced much more widely, bringing with it a number of benefits as well as a number of challenges. How has this impacted important conversations about MS progression and decisions about treatment options?

Well we all hope that we might be going back to how things were. Unfortunately, that's not where we are right now. So today we're going to explore how we can best communicate with each other about the management of MS in a telehealth world.

Specifically, we're going to be talking about strategies that will hopefully help us all have meaningful and effective interaction with our healthcare professionals during virtual telehealth conversations.

Here's an overview of our agenda. We're going to be looking at an old challenge in new circumstances, looking at communications between patients and healthcare professionals and how that has changed in our current environment.

We'll be looking at strategies for staying connected. And lastly, we'll be tackling some sensitive subjects that we hope to - and then that we hope to have time at the end to answer some of your questions if not all of them. So here we go.

Let's get started by talking about communication in MS care. And I'm going to ask Stanca, our MS patient expert to lead us off here and tell us about your experience of communicating with your healthcare professionals and how you feel that the COVID has impacted the way that you've been able to communicate with your doctors.

Stanca Porta: Hello everybody. I'm Stanca. And of course communication is a very big issue and a very big subject when we're talking about MS and how patients communicate with their healthcare professional.

And this has been an issue even before the COVID situation. There are multiple problems that arise in the communication process. So now on top of all of those with the COVID situation, the communication has decreased even more so.

From my personal experience, what I can tell you is that there are some countries, for example, Romania, where telehealth is not the norm. And we don't get the virtual conversations that we should have with the healthcare professionals.

If you don't have a private medical insurance, then you don't get the - these private virtual calls. So it's very difficult to communicate with your healthcare professionals.

Of course you can still attend, you can still go to the doctor's office but with the stress of - or the fear of getting COVID, a lot of patients just don't do that anymore. They just would rather postpone as much as they can the appointment. They would rather just keep them very short or just ignore some of their symptoms just for the fear of not getting COVID.

Amanda Montague: Thanks so much Stanca. Dr. Giovannoni, can you tell us what does the current research in literature tell us about this important topic?

Dr. Gavin Giovannoni: Oh, I think telemedicine or video consultation - I mean I think when it's done well, it's done very well. And patients that have infection rates that are very high. We ((inaudible)) just outpatients but it's like really high.

But one of the problems we have is whether the telemedicine is now delivered through web based portals for example. And then there is inequality in the world in terms of access to high speed broadband.

And so we actually - it's been quite clear that it's exacerbations some of the inequality in the sense that some people just do not have access to the right technology too. May not be an issue in the United States but it's definitely been an issue in U.K. and some parts of the other parts of the world.

The other issue is language barriers. And so much communication happens via body language and we don't pick that up - you pick up some subtleties on telemedicine portals but we don't pick them all up and that's the nature.

And also, if the person doesn't speak English as their first language and you have to go through an interpreter, you lose so much of the history. And so I'm not saying it's all negative. I'm saying

there are some - the positives on the other side is that clearly, you have contact with healthcare professionals, it saves people time and somebody not having to travel in.

And so there are all those advantages. So I think it's a balancing act like everything is, the pros and cons and we'll discuss that later on. But everyone I think - I mean I'm sure Mitzi would say that given medicine has been around for decades and some people have adopted it much earlier than others. We've been forced to adopt it very rapidly.

Amanda Montague: And Dr. Giovannoni, in terms of the research as it relates to the important and effective communication between healthcare professionals and people living with MS, what does the research say in terms of what that impact could be if there are not good communications and conversations happening at the patient and healthcare provider level?

Dr. Gavin Giovannoni: Well, I do say then - I mean we're just talking about health literacy. So if you've got poor health literacy, which is also linked to contact that your healthcare professional, things don't go that well.

I mean patients feel isolated. Its impact potentially on adherence to medication. Obviously the less understanding they have around the treatments, the less likely they are to stay a bit adherent to their therapy.

So and also this, you know, we're in this paradigm where we actually have this process called concordance where it's really a partnership between the healthcare professional or the healthcare service you provide and the individual with the disease.

And this - and that's based on trust. So you all got to bring something to the table, and you all got to contribute. And so if the communication channels aren't open in two way, particularly the

chronic disease, the relationship breaks down and this - and it impacts on outcomes. We know it impacts on outcomes.

There's well established data, for example, in relation to adherence at poor adherence in terms of exposure to medication for example. If it drops below a certain level, outcomes are impacted. So and that research is not necessarily just applicable to virtual telemedicine; it's applicable to medicine in general.

Amanda Montague: Thank you so much. I'm going to turn to Dr. Williams and ask you how has healthcare changed since COVID-19? And do you foresee these changes as being a long-term shift in the way that we communicate with our doctors?

Dr. Mitzi Joi Williams: Yes. So just as Gavin and Stanca have already kind of started the conversation where, you know, traditionally we provided care with face-to-face visits. But, you know, certainly with some form of telehealth including different private portals through the MS electronic medical records system, letters as they need to be mailed out and then in some cases emails.

The shift really has been to more electronic services. And as Gavin alluded to earlier, there are many areas of medicine where telemedicine has been around for some time. So I've been doing telemedicine for stroke for many, many years but this is relatively new in terms of the field of MS.

And so, you know, there's really been a very quick adjustment and a very steep learning curve in trying to figure out what types of systems are the best ones to use for certain patients, how do you do video visits.

If people have access to good Internet, you know, video visits are very successful. But in some cases we have to do telephone visits, which aren't as - don't provide as much information.

So I do foresee in the future there being some hybrid of our care model; Number 1, because I don't believe the pandemic is going away anytime soon. You know, I think that we'll be in this for a while as we've got this flu season and have other issues going on.

But I do also think that it does provide a lot of benefit, especially for some of our patients who live very far away, especially for some of those check-in visits where they must just have to do a medication check where there may be some hybrid where we can provide some telehealth services in combination with their in person visits, which are more traditional.

Amanda Montague: Wonderful. Thanks. Now we're going to get into some of the pros and cons. And I'd like to ask both Stanca and Dr. Giovannoni how they view the pros and cons to this new telehealth model in MS care.

And start with you Stanca and if you can tell us some of the cons that you - as you see it as a patient in terms of how this has impacted the way that you communicate with your doctor.

Stanca Porta: Okay. So first of all, there might be cons that are only valid in some areas or it depends on your country for instance. One of the largest impediments to having the virtual calls with your healthcare provider is of course access to technology, which is so different around the countries.

And even if you live in U.K. for instance or in a country that does have - that can provide these kind of appointments, it depends on where you live as a patient because people in the rural countries or people that don't have themselves access to Internet, they might find it very difficult to have such an appointment. So that's I think the biggest con.

Also, another problem that might arise is the fact that for sure the appointment will be shorter. And if it's shorter, you as a patient will not take it as seriously as you would if you would physically go to the doctor's office.

If you go physically to the doctor's office, you prepare for it ahead. You just take your car, you think about it; okay, tomorrow I have to go to the doctor's office. So it's a lot more of a preparation than it is just a phone call or just a video call.

So the video call you don't need to do anything. No preparation. You just call him in your - from the comfort of your home, which is okay, a good point. But what I'm trying to say is that it might reduce the importance of the meeting with your doctor.

So - and also, a lot of - it depends on the patient. Some patients might have a cognitive or visual or audio impairment. They might not know how to use technology. They might need the help of family, friend or - so there are so many impediments that depends on person to person.

So - and also, it feels very less personal. The contact feels less personal because you're interacting with a screen basically or with a phone. It's not as personal as it would be when you see your doctor face-to-face.

The doctor can see you and can see your reactions, can see if you walk very well or walk very bad for instance. If you just talk to him on the phone, you have to describe how you walk for instance as an example. So these are the major cons sort of to say.

Amanda Montague: Thanks so much Stanca. And I think we can all relate to those cons. And those do provide some real challenges in terms of telehealth. Dr. Giovannoni, can you tell us some of the pros to telehealth in MS management?

Dr. Gavin Giovannoni: So yes, the pros are pretty obvious in terms of time saving and cost savings in terms of transport and getting to hospitals for example. And obviously with COVID-19, reducing

your risk of unnecessary exposure to - and potentially hazardous environments in terms of the coronavirus spread.

But I do want to disagree with Stanca. I personally don't think there's any time saving. If you take your consultation as seriously as you do with a face-to-face, you still want to exchange the right information.

And so, you know, we have a pro forma that we go through to make sure we don't miss anything. And I think that doesn't change. I personally don't think my telemed consultations are any shorter.

And we also developed a little protocol using a smartphone on how to do a virtual examination. So we can access eye movements, upper limb function and walking.

And the point about that is you've got to prepare the patient. So you send them information beforehand so they know what you have at hand and the space cleared in their home so that you can see them walking, for example, if you need to examine gait.

But I think the real advantage is we incur in patients by giving them instructions of - on self-monitoring so we can get them to get their EDSS scores for example, disability scores using a calculator online. They do their own apelin function and walking times. And they prepare a list of questions beforehand.

So I actually think, you know, when you actually think about what you want from a consultation, you can actually use this change in the way we practice to find a much better consultation.

So the other thing about it is - is because these virtual rooms you can bring in people from all over. You can bring in three or four, five people. Sometimes you can bring in a relative they want who doesn't live with them, you know.

So just to give you an example, I had a patient who was trapped in Singapore during lockdown. She came into the virtual consulting room. And I had her mother who was living in London come in. And that would not be possible potentially in other situations.

So there are real advantages that - off of that. The other thing I find is it's much easier to share information because all you do is you share your screen on your computer and you can bring up other things and show them YouTube videos, whatever.

So I actually think - I actually - this is why I don't think we're going to go back. We're going to take the best out of this experience forward. And I reckon we're going to be going - and I agree with Mitzi. We're going to be going into a hybrid model.

So Stanca, you need to come live in - you need to come live in United Kingdom or in the United States, I think.

Stanca Porta: Okay.

Amanda Montague: Come on Stanca.

Stanca Porta: It sounds - I think what he said it sounds very good. But I'm telling you that it would be very difficult to implement those changes into countries like Romania. So I don't want to go live in U.K. I just want to implement them in Romania.

Dr. Gavin Giovannoni: I know.

Stanca Porta: Can we work from there?

Dr. Gavin Giovannoni: Yes. I...

Stanca Porta: I mean the healthcare system here just lacks all technology. So that's one of the biggest problems.

Dr. Gavin Giovannoni: Yes. I think one of the problems I picked up and I might as well bring it to the table is that in certain countries - I'm not talking about Romania. I don't know what happens in Romania.

But there's one particular European country where the reimbursement for telemedicine is so much lower than face-to-face despite no time saving. And so until the perverse incentive in terms of money changes, that particular country is unlikely to adopt telemedicine because their neurologists and the healthcare system just find the economics of telemedicine too, you know, it's not sustainable.

I'm not sure if this has happened in the United States if there's different tiered payments for telemedicine versus face-to-face. But I think the payers must realize at the end of the day the quality could potentially be identical or maybe even superior using a video consultation and they should reimburse the clinician for their time.

Dr. Mitzi Joi Williams: Yes. And so that was actually a challenge I was...

Amanda Montague: So Gavin, you have led us wonderfully. Yes.

Dr. Mitzi Joi Williams: Yes. I was going to say that was a challenge that I was going to bring up is that here in the U.S. there were temporary changes that were made while there were, you know, an official state of emergency but now some of the states are easing their regulations whether they should or not.

There are some payers that are pulling back and saying that they won't reimburse for the telemedicine visits, which are forcing people to go back into the office.

Amanda Montague: So in the vein of what we were just discussing about how things are different in different areas of the world, I'd like to get all of your takes on what access is like in terms of face-to-face consultations at this point.

So Stanca, start with you. Are you having face-to-face appointments with your doctors in Romania? And if you aren't, how are you able to talk about issues like progression with your doctors in a telehealth platform?

Stanca Porta: So right now the only way to get an appointment with your doctor would be physical consultation. You can have call like a phone call with the doctor, but you cannot have a video call. That only happens if you go to a private practice.

Well I - there are some people that access that, but they are so - they are not relevant to the entire system so to say. I personally don't go to the doctor because I don't need to right now. So I'm happy and glad about that. I'm lucky.

But other people I'm - other patients with MS, they just address their most urgent needs or their - if they have a relapse, if they have something really urgent they need to take care of, then they go to the neurology.

But other than that, they would just - not ignore but maybe postpone their symptoms. And for sure they don't address progression right now unless it really happens like I said with a relapse.

If they are not having a relapse right now, they would rather just keep the appointment short or just talk about the pressing issues right now or and don't address the progression issue, which seems like a really long conversation and something they can just postpone after - and deal with it after COVID.

Amanda Montague: Thank you for that Stanca. Mitzi, I'm curious. What - how would you describe the number of face-to-face appointments you're having with patients versus telehealth these days? And have you found working with patients through virtual means - any problems in terms of really making assessments on progression or symptom management?

Dr. Mitzi Joi Williams: Yes. So, you know, it really depends on where you live here in the U.S. So there are some states that are very liberal in terms of having everything open. I live in Georgia. And that is basically one of those states.

So at the hospital practice where I see most of our patients with the teaching - the students and residents pretty much almost all face-to-face, very little telehealth. The waiting rooms are packed with patients.

And then if you go down the street to a private practice - in my personal private practice and still see people majority telehealth unless it's a new patient that I need to assess in person.

So, you know, and then I think if, you know, you talk to somebody who's in Boston, they're doing 80% telehealth and 20% face-to-face. So I think it's really, really varies here just depending on where you live and the regulations.

I would say in terms of challenges overall when I've been able to do video visits, they've gone very well. I feel like the conversations are very targeted. Patients do have, you know, kind of a list of questions. We try to prepare them beforehand.

And I feel like the visits are very targeted and go very well so people don't have to complain about parking, things of that nature; or Atlanta traffic, which could be terrible. So they're usually pretty relaxed because they don't have to ride in our traffic to get to the visits.

But I have had some challenges especially with some of our older patients who may not have a handle on how to use the technology well, especially on their phone. A lot of people are using their phones and not necessarily a desktop or a laptop.

And so sometimes there have been challenges with connecting to websites. And sometimes we've had to as a result do telephone visits, which make the assessment very difficult.

But for the most part, the virtual visits, especially when they have a video component have gone extremely well. The patients love them. And we work very well with them.

Amanda Montague: Great. And same question for you Gavin. How many patients are you seeing face-to-face at this point versus through telehealth? And have you found any impediments to telehealth in terms of being able to monitor progression or help patients with symptom management?

Dr. Gavin Giovannoni: No. I think in terms - at the moment our ratio is about 20 to 30 face-to-face, 70 telemedicine. And the reason for that is not us at our hospital because we're still in the second surge and we don't want the patients to come sit in waiting rooms. We've got to socially distance the waiting rooms.

So we have a maximum number of people that can come at any one time and that's what dictates the face-to-face. But any patient who insists on a face-to-face gets a face-to-face to be honest with you.

But a lot of them don't want face-to-face. And my personal preference is for new patients is to have a face-to-face simply because you want to examine them and do a proper job. And it's very difficult to see a new patient online without getting a full picture and a good feeling about it.

And in terms of progression, I personally don't think the issue around progression starts when you have telemedicine or you don't have telemedicine. It's a discussion that happens over years. Should probably - you know, it's not something you just have - you bring up one day. It's opposite - I personally think it's an ongoing discussion.

It's about educating your patients about what MS is and what the disease is. So I don't think this has changed that discussion at all. What has happened in the initial consultations because of COVID-19 dominating and some of the time was spent talking to patients about the risks of COVID-19, how they should manage themselves.

So that consumed quite a bit of the time. But that's expected because that was the issue of the day. Now that that's passed away and most of our patients understand what to do, all the old questions are coming back up again.

I think what has changed though is we've actually given patients instructions and we referred them to various web resources or provided them with new web resources on how to self-manage, you know, what to do with your bladder before you complain to your MS nurse about what can you do. How do you handle your bowels? What can you do for specificity?

So we've given them a whole lot of detailed instructions about self-management. And obviously when they hit the dead end, they come to us and say I can't go through it. And then we get in it.

So I actually think this is a - I mean it's a positive thing. We actually encourage our patients to be more in control of their disease and understanding it more. So I'm actually - I'm going to be - I'm going to be the optimist. I think COVID-19 is going to be a very good thing for the healthcare system.

Amanda Montague: Well, I think we will all join you in your optimism because we could all use some of that right now. So that's really good to hear. We are going to move onto the next piece of our agenda, strategies for staying connected. And Mitzi, I'd like to turn to you and ask what advice you would give people living with MS for adapting to virtual consultations.

Dr. Mitzi Joi Williams: Absolutely. So many of the things that Gavin has, you know, talked about.

Certainly, we want people to prepare for the conversation. So you know, as Stanca said, there could be this perception that just because you have to hop on a call, you're sitting at home maybe in the middle of doing something, you may not have as much preparation in terms of your visit being on your mind while you're driving in the car and traveling, et cetera.

But certainly we want people to prepare for the conversation. So have them with the questions, things that they need to be addressed. I would love to have family members near if they're available to participate in the conversation, which as we've discussed earlier, is a little bit easier in a virtual environment especially if people have to work. They can just take a few minutes and hop on the virtual call.

We also want people to consider the environment, kind of where they are. So, you know, I try to prepare my patients and tell them they need to be in a quiet place, away from distractions.

I've had several people who I've called and they've been kind of walking through the grocery store or, you know, working. And I'm like well, you know, maybe we need to reschedule because you're in the middle of Wal-Mart and it's probably not the best place to do a doctor's visit.

And then also appropriately dressed, you know, so that something that, you know, you think you wouldn't have to throw in there, but you do. We can see you. So you want to be appropriate dressed.

And then of course, you know, as Gavin said, it gives us a good opportunity to direct people to different online resources and to help make sure that they're getting valid information about not only COVID-19 but MS and also to empower them to educate themselves and to do things that they can do to live well within that.

Amanda Montague: Super helpful tips. I'd like to ask Stanca. How has COVID-19 impacted your discussions with your doctor?

Stanca Porta: Sorry, I was on mute. So for sure it impacted the communication and the discussion. And I feel there is a need for the telehealth. If ideally could be implemented, it would address a lot of concerns. Because right now with the COVID situation added, there are more concerns around discussion that you have with your healthcare professional.

So first of all, just going to the hospital would be a concern for any patient or for anybody just because you get of your house and you get exposed to maybe somebody that has COVID in traffic while going to the hospital or maybe in the waiting lobby or just being outside your house is a concern.

Then it's also how does COVID impact my MS? If I'm a patient with MS, having COVID would definitely be worse than just being a regular person. It depends - also, it depends on what medicine, what treatment I'm on.

There are some treatments and I'm sure Gavin and Mitzi confirm - can give us details about certain medicine, certain treatments that affect worse or less worse the - just the fact that you are on them. You might get a really bad case of COVID.

So these are all additional concerns. And you might just - as a patient when you go and have your consultation, you might just skip some of the less important symptoms in your mind and you just might address the bigger ones, the bigger issues. And that's - these are some challenges that of course changed since the COVID.

Amanda Montague: And Stanca, I know you had mentioned before that - and you alluded to it now. But I think it's really important to highlight that perhaps for some folks who only have the option of going in to see their doctor, it might even be impacting their ability to have any conversation with their doctor.

Stanca Porta: Yes, of course. Because like I said, there are at least in Romania the medical healthcare system as a system does not have a digitalization solution. So and a lot of people just rely on the physical consultation.

And now they are just afraid to get out of their homes and they just don't do it. They just would rather deal with it at home or they would rather go on - actually online and on Facebook and Facebook groups and just talk to somebody else and ask opinions there because they cannot reach their neurologist - and it's a big issue.

And of course again, it depends on the patient because you - if you have access to private care, you can call your neurologist. But if you don't, if you go to the public healthcare, then you don't have the personal phone number of your neurologist and you don't - you cannot even call him.

Amanda Montague: I think those are all really wonderful points. And I think it speaks to the fact that patient preference is really important during these times. And so I know we touched upon this a bit before but to Gavin, given some of those certain - certainly some challenges for patients who might be foregoing seeing their doctor because of fear of COVID, how much flexibility do you think we have in our healthcare systems even though they're all slightly or very different to be able to accommodate these patient preferences to ensure that people have access to their doctor even in the midst of a COVID pandemic?

Dr. Gavin Giovannoni: But I think that - I mean I'm sure it happened in the United States in some parts of the country where people redeployed away from their normal jobs into others.

I was actually redeployed too and worked in a COVID ward, for example, for six weeks. But I still had to make time after hours to try and continue my job as an MS expert.

And I was - therefore, I created what I would call asynchronous communication channels where you didn't have face-to-face time. You would - created a portal for patients to ask me questions and I would respond to the question.

And I thought well, if the question was relevant to Patient X, if I anonymized the question, I could actually be speaking to many patients all at once. So that kind of helped.

And the avalanche that we got to - I mean the first few days I was getting literally 40, 50 questions a day. And over six or seven weeks it dropped right down to one or two questions a day and even eventually petered out.

So there are ways of protecting your healthcare system to deal with the crisis like COVID and at least allow people with a disease to understand that there's somebody there.

But I'd also - at the end of the day though, it's a, you know, we're in a service industry. We need to adapt. And so I mean people don't like that because some people think healthcare is a basic human right, which it probably is. But, you know, obviously the quality and the kind of service you provide has to be appropriate for the times.

Should we - would I have changed anything? I would change a lot now knowing what I knew back then but we just had to go on the fly. It'd be quite interesting to have other people's experiences because Stanca's coming from Romania where there are issues around access to healthcare and the way their healthcare services configure.

But there are other parts of the world where I suspect in the United States, for example, that varied dependent on where you live and how much healthcare insurance you had an who was looking after you. Because I'm aware of some services being highly reactive to the COVID-19 pandemic and they didn't change their level of care they gave their patients at all.

They were still doing, you know, very high quality care in terms of even starting or maintaining people on infusions. I think it's going to be - when the dust settles, I think we're going to get a really mixed picture of what happened.

Maybe we should actually step back and learn and prepare for this next time and share best practice and share what we've all learned and try and have a proactive approach that if something like this does happen again, we're much more prepared for it. I don't think - I don't think I've answered your question. I'm sorry Amanda.

Amanda Montague: No. You did Gavin. It's perfect.

Dr. Mitzi Joi Williams: I said the only thing I was going to add is that something that was very great that Gavin did was create a micro site with many of the questions about COVID-19 that patients asked.

And I actually directed a lot of my patients to that micro site to get information because every - many of the calls in the beginning were specifically about COVID-19. And if you have 50 people calling about the same thing, if there's a resource that you can direct them to, it's very helpful.

So I've really thought that Gavin and his colleagues did a great job with the micro site and with the Webinars that they were doing on a fairly regular basis about very hot topics about COVID to just kind of try to help the patient and healthcare community understand what was going on.

Amanda Montague: And Gavin, would you be so kind as to share with the audience what that - how they could find that micro site that Mitzi is referencing?

Dr. Gavin Giovannoni: I think if you just - I mean it's called - I mean the actual site is - was in development. The site's called MS-Selfie like selfie self-photograph or MS self-management. And I just basically created a new section on it for COVID-19 if you find it.

But to be honest with you, people - I'm sure Mitzi and Stanca, everybody's COVID out. We just don't want to know about it anymore. So the less you know about it now, the better. I don't think people are nearly as anxious as they were in the beginning.

And if anything, people don't want to know about it anymore. And so I'm actually - I actually find that when I do my consultations with patients, they don't want to discuss COVID-19. They want to discuss their MS and other issues.

So hopefully that micro site has learned a lesson and I'm busy working on finishing it. And it'll be - it'll all be a portal for people to self-manage essentially and try and provide - it's quite a high level. I must be honest with you.

I don't believe in - this is one of the things. I don't believe in being patronizing. I believe in writing at a quite high level. So some people may find it a little bit technical. But I find it very difficult to dumb down important information.

You know, some people could ask question but at the end of the day, you know, some of the information has to be high level because managing MS is quite a complex issue and you have to explain things like - let's give an example. Neutralizing antibodies. There's no easy way to explain it and but at a high level for example.

Amanda Montague: Wonderful. Thanks. And I will just throw out there another resource for folks that's specific to COVID-19 and MS is the COVID-19 MS Pathfinder, which can be found on MSAA's website, mymsaa.org. So that's another thing to check out if you have questions. And that is updated weekly with new news and facts as it comes in.

So next we're going to move on to tackling sensitive subjects. And we have a number of questions from folks who are on the line right now. So we're going to try to move through these next couple of slides pretty quickly so we can get to some of the questions.

But I did want to start with asking Mitzi around difficult conversations either pre-COVID or currently. How do you usually speak to your patients around progression? Is it something as Gavin mentioned earlier that happens from the beginning? How do you handle that conversation?

Dr. Mitzi Joi Williams: Yes. So I absolutely agree that it has to start at the beginning, right. And so I think that there are different levels of detail of that conversation depending on where a person is in their journey with MS.

But certainly in the beginning we talk about it because when we talk about initiation of treatment and we talk about our goals, one of our goals is to try to delay progression.

And so especially when you're talking to a person who may not currently have symptoms from their MS, who may have had a relapse and have fully recovered very early on in disease, we know we have to talk about why we want to start a medication that may affect your immune system, you know, and why we need to take that indefinitely.

And certainly, one of the things we have to address is that MS untreated is often a very progressive disease. And so I think that that initial conversation starts in the beginning.

And then at different points it's really an ongoing conversation but especially if people have relapses or they have certain worsening of symptoms when we come in for our consultation whether that's in person or virtually, we readdress it. So I consider it an ongoing conversation that starts really from the very first visit.

Amanda Montague: Wonderful. And I know for the audience, at least for those not familiar with the MS in the 21st Century survey, the group did a survey around disease progression. And I'm wondering Mitzi if you can tell us how those findings align or don't align with some of the - some of the insights that were gathered in this survey around progression.

Dr. Mitzi Joi Williams: Yes. So what I love about MS 21 is that, you know, there's a lot of work focused on improving patient and healthcare provider communication. And the survey was a great

example of how sometimes there's a disconnect between what HCPs believe that patients want to hear about and what patients actually want to hear about.

So when we looked at the results, there were about close to 500 responses. You can see here on the slide. And neurologists thought that probably about 40% of neurologists talked about disease progression at the onset of diagnosis versus nurses talked it at treatment initiation.

But one of the key points that I thought was interesting was that nearly 50% of HCPs didn't want to talk about disease progression because they felt like it would upset the patient. But only about 16% of patients agreed with that.

And then a large number of patients, close to 20% were just waiting for their doctor or healthcare provider to bring it up. And there were also significant number of patients who said, 27% - I'm sorry. There were a significant number of patients who said that their healthcare providers never talked to them about disease progression, 32%.

So I think that we have to have these conversations that, you know, even though it may be upsetting, patients do want to hear about it. And they do want to know about the full extent of disease.

So there's some gaps that we need to bridge between what healthcare providers think that patients want to hear and what patients actually want to know and talk about.

Amanda Montague: That's wonderful. And Stanca I'd like to follow up with you in terms of what you think some of the common misconceptions or misunderstandings are out there about progression from a patient's point of view.

Stanca Porta: Okay. So first of all, I would like to agree with what Mitzi just said that even though it seems like us patients don't really want to address progression, we do. But we also fear the answer. So that's why we might seem upset when we discuss the subject.

So it's a very difficult subject for everybody to handle or discuss. But at the same time, we really do want to know. So that's why it makes it so much more difficult.

And one of the most difficult things and one of the misconceptions around the term progression is the fact that it's often just representing the patient's mind. It presents progressive MS. So just the fact that it sounds like progressive MS, it means that it's super serious, so, or severe.

So when you talk about these - when the healthcare professionals for instance starts the subject and he says, okay, let's talk about your disease progression; you automatically think that it's progressive MS. So that's one of the maybe misconceptions and why patients don't want to address it.

So just - and like Gavin started and actually Mitzi also said that it's an ongoing conversation. I feel like that's the most important thing. That you start talking about progression from the start, but you have to be careful on what you address first and how you develop into the subject further on.

Because right from the start when you're a newly diagnosed patient, at first I did not agree that it's a good time to talk about progression just because you are receiving the news that you have MS. So we have to deal with that first.

But when is a good time to start talking about progression? You feel like you need to be informed over time. So you should start right at the beginning but maybe in small steps. And just have you build up and with time to just have a full understanding of what progression really means.

Amanda Montague: Thank you so much Stanca. I want to give everyone a quick resource and a call to action. There's some things that you can definitely consider as we've heard in this webinar to really prepare for your next virtual consultation. And My MS in the 21st Century has a wonderful resource that you can try see one the webinar right now; how you can access that.

You can also visit mymsaa.org to get some much-needed resources about preparing for your next visit. But this is a really important question. And I think the piece that we all clearly agree on is that we're going to be here for some time. So it's important to figure out how to do this right.

And I want to - before getting to the questions from the audience, want to just say thank you so much to Gavin, Mitzi and Stanca and MS in the 21st Century and certainly our sponsor EMD Serono for letting us put this together. I think it's a vitally important topic right now that we all could use some help with. So thank you for that.

And now I'm going to turn it over to some of the audience questions. I will ask Mitzi. We have a question: If a patient takes appropriate precautions regarding contracting COVID-19, is there any reason they should be fearful of attending a in person appointment?

Dr. Mitzi Joi Williams: I mean so I would say certainly we are doing the best we can in terms of, you know, contact precautions. We know that masks make a difference. I don't know that any of us could ever say that if you wore a mask there's 100% chance that you could not get COVID going to an in-person doctor's appointment.

But certainly most doctors' offices have put many things in place in terms of social distancing, checking temperatures and things of that nature to make it as safe as possible, you know. But there's no 100% guarantee that you couldn't get COVID with taking precautions but certainly it's much safer than it would have been back in March or back in February.

Amanda Montague: Wonderful. And this one is for Gavin. Jane was inspired by your optimism in terms of how doctors are preparing for telephone consultations. And she asks if anyone's developed a standard practice for telephone consultations and in particular assessing over the telephone cognitive and mobility issues.

Do you know if there's something out there as a tool that either your Center is using or if there's something that might be more widely available for patients or healthcare professionals to take a look at?

Dr. Gavin Giovannoni: No. So I mean I'm not sure anything's being standardized. That's one of the problems in this space. There's so many different online apps and various scales for measuring the impact of MS.

I think you really need to speak to your own healthcare professional what suits them. I think the biggest problem in adopting a standard is that is to have it incorporated into what we would call the work streams that goes into electronic patient health record and it's like a tracking system and it gets measured every time.

And that's going to depend on individual healthcare systems. So we use the - we use EDSS because that's what's standardized in the - in clinical practice and we like to anchor it to EDSS. And because we can't do it in person, we have this calculator which we validated. It's on a website called clinicspeak.com. And there's a whole lot of things you can self-monitor with.

And I think - but it's important that you do it yourself if you're a healthcare professional is not doing it. So you got an idea and you're - knowing about progressive MS or worsening MS is monitoring yourself.

Actually, to be honest with you, most people with MS know when they're getting worse. You know, it's - you don't have to hide it from them. They actually - they know long before you tell them they've got progressive MS because they've been monitoring themselves. They know their walking distance is going or they know the apelin function is not as good as it was. Their balance is not as good as it was.

You know, you can't - as an individual with the disease, you can't hide those things from yourselves. So this idea that people with multiple sclerosis aren't prepared for confronting the fact that they're worsening is ridiculous because they're living with the disease.

So this - that survey showing that neurologists or healthcare professionals don't want to talk about it is just begs belief anyway. So no. I don't - there is nothing standardized at the moment, so.

But that's something that the MS community should get together and do something about because, you know, there should be a standard like everything else. Because if there is a standard, people will aim for that standard and it will drive up quality, drive up, you know, what we're trying to do in the MS space.

Amanda Montague: Agreed. I think that - I think that's a brilliant idea and is something we should all work on together to have for the MS community. Another question, which I think is probably on everyone's mind is anxiety. And I'll ask Stanca. You know, with everything else in terms of living with MS, how has anxiety played a role in terms of how you manage your MS and how you feel about daily living with MS?

Stanca Porta: So I feel like the anxiety levels have definitely - are definitely higher right now with the COVID situation. But at the same time - and also, I think there is also another issue that needs to be addressed; the fact that the economies have all been affected in different - in various ways.

And a lot of people have lost their jobs and a lot of those people have MS. And so there are some collateral damages sort of to say. So people with MS have the additional stress right now of finding a job or keeping a job in these conditions.

Of course it's better for a person with MS to work from home. So that's a good thing that we can all work from home right now. It's a good thing. But on the other hand, a lot of people just lost their jobs. So that's added anxiety right there and of course just catching COVID, which we discussed.

Amanda Montague: Thanks. And for Gavin and Mitzi, kind of the flip side of that question; do you feel that it's difficult for patients to tell you over the phone talk about feelings of anxiety or even depression? And do you think that that's something that needs to be proactively addressed with patients when you're talking to them?

Dr. Mitzi Joi Williams: I do think that - so I think that period it should be a proactive conversation. But I do think that patients have been very candid. I would say as Gavin said earlier, that COVID is not the primary conversation for most visits at this point but certainly there's a lot of fatigue especially here in the U.S. with a lot of the issues that are going on with the pandemic as well as other kind of social issues.

So people are very open to talking about it. But I definitely, you know, feel that it should be a proactive conversation that we have with patients about any new issues related or unrelated to COVID.

Dr. Gavin Giovannoni: I actually think that it should be part of the pro forma in the sense that every consultation, the neurologist, or the healthcare professional should address what we call the hidden symptoms. People that, you know, and part of that would be mood and anxiety.

I think we should actually ask or use strategies to bring the person with the disease opportunity to discuss those symptoms. If you don't - if you've not been given the opportunity to discuss those things with your neurologist or your nurse or whatever, then there's a problem with your relationship if that helps with the question.

Amanda Montague: Great. And then this one is for both Gavin and Mitzi. And Gavin, I'll start with you. As physicians, what do you think are the biggest down sides of telemedicine visits, what do you feel is missing the most and when would you encourage patients to see you in person?

Dr. Gavin Giovannoni: So obviously the downside is the body language. You just don't pick up some of the subtleties. The other downside is some of our assessment of patients in terms of getting information is an examination. And the online examination is just not good enough for that.

And so those are the big down sides. But, you know, when you balance them with the plus sides in the current environment, it's not a bad tool to be honest with you. But the last question of - the last section of that question I didn't - I've forgotten it.

Amanda Montague: When would you encourage patients to come and see you in person? And I think you mentioned certainly for our first-time patient.

Dr. Gavin Giovannoni: Yes. Our first-time patient when there's an issue around access to technology, when there's also an issue around using an interpreter for example. What else would I say? Yes, that's about it because most of the other things you can do using a virtual platform to be honest with you.

Amanda Montague: Wonderful. And Mitzi, do you have anything to add on that one?

Dr. Mitzi Joi Williams: No. I think Gavin said - I echo his sentiments exactly. That's exactly what I would do as well.

Amanda Montague: Great. So we have two last questions. One follow up - is a follow up question to the anxiety question. But I think it's probably one that is no pun intended stressful to many patients. Is there any concern from a physician side that the higher levels of anxiety or stress that we're all living under right now might actually further progression of MS or exacerbate symptoms?

Dr. Mitzi Joi Williams: I can give you my thoughts. No, you go ahead Stanca.

Stanca Porta: As a patient, I know that stress is a really big issue with MS and it might just cause another relapse when you're stressed or you have anxiety. So anything that adds anxiety and stress in your life can help you progress your disease. So it's not good. So just - I'm showing that is a big issue.

Amanda Montague: Yes. Mitzi...

Dr. Mitzi Joi Williams: Right. So...

Amanda Montague: ...what do you think from a clinician standpoint?

Dr. Mitzi Joi Williams: Yes. So certainly, stress and anxiety do make people feel worse. I don't know that we have a lot of evidence, and Gavin can also add to this, that actually suggests that stress would make someone have a new lesion in terms of a relapse in that way.

But certainly people can temporarily feel worse if they're under an extreme amount of stress. And we certainly recommend that people try to keep their anxiety levels down.

Amanda Montague: Wonderful. And Gavin, do you have anything else to add on that question?

Dr. Gavin Giovannoni: No. Nothing at the moment. All I can just say is that, you know, the good thing about storms is they come to an end. So this will come to an end.

Amanda Montague: Again, we are all loving your optimism today. So...

Dr. Gavin Giovannoni: Yes.

Amanda Montague: Finally our last - our last question comes from an esteemed member of the MS in the 21st Century Steering Committee, Trishna. And she asks if we can share - this is a question for all three of you. Are there specific resources that any of you might recommend for people with MS to learn more about self-management?

Dr. Gavin Giovannoni: I mentioned my MS-Selfie site but that's still not quite up for prime time. But I think if you just engage with the MS societies, the MS Trust. You need to also probably look locally because some of the issues around MS management definitely are cultural and local.

And so look locally. I'm sure there must be resources in your area provided by the MS Society branches, you know, by yourselves for example that can help with self-management.

Dr. Mitzi Joi Williams: I would also say MS - well I was also going to say MS 21. MS 21 has some great resources. So there's the MS companion tool and then there is also a kind of online, almost like a

workbook where people can write questions and prepare for their doctor's visit. So there are a lot of great resources on the Web site as well to help with self-management.

Amanda Montague: Great. And Stanca?

Stanca Porta: I was just about to say the same thing as Mitzi did with resources we have at MS in the 21st Century. But also it would be a good idea to just ask your neurologist what - how you can - what you need or your - just address your question and ask him to recommend something that works for you because he knows you better or your team - your entire healthcare team.

Amanda Montague: Wonderful. And I will say for those who are not familiar with MSAA, we also have some great resources on this topic including a wonderful app called My MS Manager that really can help with self-management. So check us out at mysaa.org if you haven't already.

My sincerest thanks to EMD Serono for sponsoring this webinar. And just again, thank you to Gavin, Mitzi and Stanca for taking the time today to be with us. These are really important conversations, and it was good to share them with all of you. So thank you.

Dr. Mitzi Joi Williams: Thank you.

(Sanka Potrar): Thank you.

Dr. Gavin Giovannoni: Thank you. Have a good weekend.